Cancer Control interviews Dr Miriam Mutebi, President of AORTIC

Dr Miriam Mutebi is a Consultant Breast Surgical Oncologist and Assistant Professor in the Department of Surgery at the Aga Khan University Hospital in Nairobi, Kenya. She is also a clinical epidemiologist and health systems researcher with a research focus on understanding barriers to access for women with cancers in sub-Saharan Africa and in designing interventions to mitigate those barriers.

She is the President of the African Organization for Research and Training in Cancer (AORTIC), a member of the education and training committee for AORTIC and past-President of the Kenya Society of Hematology and Oncology (KESHO) and on the board of directors of the Union for International Cancer Control (UICC). She is also the co-founder of the Pan African Women's Association of Surgeons (PAWAS – www.africanwomensurgeons.org) and is part of the Kenya Association of Women Surgeons.

She is also co-Chair of the National Cancer Taskforce in Kenya, Chair of the Commonwealth Taskforce for the elimination of Cervical Cancer and a Commissioner on three Lancet commissions. She is a lead on the African Cancer Survivorship Working Group that is dedicated to developing continental research that reflects patient reported outcomes and quality of life and has developed and helped implement both local and regional cancer policy.

CANCER CONTROL: Dr Miriam Mutebi, you're the first female breast cancer surgeon in Kenya and the co-founder of the Pan African Women's Association of Surgeons. You're the president of African Organizational Research and Training in Cancer (AORTIC) and last year you were awarded the ASCO Humanitarian award. How did you get here? How does anyone get to that position? Tell us your journey.

MIRIAM MUTEBI: Probably a whole lot of stubbornness, I guess. You know, growing up in Nairobi, one of the things that I probably, like most people after high school wondered about, was how to start…. You asked "What's my journey?" Somebody else had that same question asked to them in an interview, and they started with this song: "I was born by the river in a little tent… And just like that river I've been running ever since..."

CANCER CONTROL: Sam Cooke! He wrote that. Change is gonna come.

MIRIAM MUTEBI: Exactly, "a change is gonna come". I love that guy. Anyway, hopefully, we won't go that far back to my beginnings. But you know, like every bewildered teenager, by the time they finish high school they have ten million different things they want to do. For me, I always had. And for me, I always had five different things that I wanted to do. I wanted to do law. I wanted to do pharmacy. I wanted to do medicine. I wanted to write. I've even tried my hand at bad poetry and prose in my youth! And architecture. So it was, okay, I like all of these. I'm good at them. How do I decide on which direction I really want to go in?

CANCER CONTROL: How did you decide?

MIRIAM MUTEBI: By talking to my parents and listening to their advice. Because we usually have a gap year and that allowed me to spend a bit of time at each of these professions and kind of decide what it is that I wanted to do. And so, I ended up working at a publishing firm. I ended up shadowing a pharmacist and helping to count pills behind the counter. I got time at a law firm and at an architectural firm, and then I ironically actually got to volunteer at the Aga Khan University Hospital..

CANCER CONTROL: Where you are working now?

MIRIAM MUTEBI: Yes, this is my current employer. So I got to spend a bit of time trying different things. At the end of it all, it came down to the two things: medicine and writing. And so, I go back to my Dad. And I'm like "Dad, what do I do? I want to do medicine, and I want to write". And he says "Well, if you do medicine, you can still write. If you write, you might not be able to do medicine." And so that's kind of how I got into medicine.

CANCER CONTROL: And so you went to medical school. What was that like?

MIRIAM MUTEBI: I was in medical school in the early 2000s, just as we were coming to the tail end of the HIV epidemic, but we still weren't having much access to antiretrovirals. So it was actually a very grim time, I would say. This is certainly not the case currently with better programmes and with a lot more access to antiretrovirals, with normalization of HIV, which has become like any other chronic illness. But when I was in medical school, then there was still a lot of stigma around a diagnosis and unfortunately some patients would get abandoned at the hospital. So, you could find in the medical wards – and we'd have, maybe, six wards in total – that maybe the first few wards were full of patients who were having acute medical conditions like pneumonia or renal dysfunction, who were being treated actively. And then a significant number of the remaining wards had patients who had been abandoned by their families. They were basically getting supportive care and were at different stages of succumbing to the disease or its complications. And that was pretty grim, because then they didn't necessarily have access to as many medications and antiretrovirals. It's a totally different experience for those doing these rotations currently.

CANCER CONTROL: How did that feel?

MIRIAM MUTEBI: I would say there was a sense almost of helplessness, maybe even hopelessness, in that setting. Then one would go three floors down to the surgical ward where a patient comes in and they have an acute abdomen problem. You take them in, they have surgery, they go home, and they're like "Thanks Doc!" And for me, it was like "Where can I make an impact?" And so that's how I wandered into surgery. Which is probably a very different experience now because HIV is like anything else – you treat it. You wouldn't even be able to tell who's suffering unless they disclose it. But that's what shifted me into surgery.

CANCER CONTROL: What led you to specialize in breast cancer surgery?

MIRIAM MUTEBI: In surgery we have what we call "end-of-rotationitis", where you complete a rotation and you're like "Ooh, I want to do that". You do orthopaedics and you're: "Ah, I want to do this".. You do urology and you're like: "No, I want to do this". For me, I think the striking thing was when I was in my breast rotation. In all the books I had read the description of who gets breast cancer was basically a lady in her sixth or seventh decade. At the time, the poster child for breast cancer was the "Nulliparous Nun", a woman who never had children and had never breastfed – all of which are supposed to be traditionally protective factors – and maybe in her sixties or seventies. And I'm sitting in on clinics and I'm seeing patients in their thirties and forties with multiple children all breastfed, with none of the traditional sort of risk factors. And I asked myself "What is going on? Somebody needs to get to the bottom of this."

CANCER CONTROL: So, what did you do to address this?

MIRIAM MUTEBI: We used to do two things at my institution where I trained. The first was a monthly screening by the nurses where we would have ladies coming in, getting a clinical breast exam (CBE) and if there's any concern, they get them sent and seen by the doctor. As the resident, you frequently drew the short straw, and had to sit in for the duration of these monthly weekend screenings. But then I started to realize that a significant number of the referrals were inappropriate. Somebody being told "You have bilateral breast masses" and you're examining the breast and you can't feel anything. And you're like "Okay, this is clearly a problem." Right? A problem even within the healthcare workforce around what is a good CBE? And so, for me, I'd think this is a space that really needs to be developed and expanded on.

And then the second thing was that we, as obliging residents, used to volunteer to do a lot of talks and public awareness work, especially with our cancer support groups. And what stood out for me was one time when I was talking about the complications of mastectomy. I'm sitting there, giving them the rundown, saying "Your surgeon will have told you about this, that, and the other..." and you can always tell when you're giving a talk and you're reading the room and everybody's kind of looking a little like they're staring into the headlights. And you're wondering "What is going on?" But you still give the talk, and you think maybe I'm making it too technical. No, I'm communicating in fairly simple language. But they still have this look…

CANCER CONTROL: Yes.

MIRIAM MUTEBI: But then, later on, after the talk, a group of ladies called to me and they pulled me aside, and they said "You know, Doc, you're telling us this fairy tale about where your surgeon actually talks to you and explains what's going to happen with surgery!" And I'm thinking that's not right.

I had a 65-year-old, a lovely lady. She had a DCIS and, unfortunately, she had a modified radical mastectomy, which is a lot more aggressive surgery than we would usually do. But she had really horrible lymphoedema, and she said that she was 65 (she's much older now) and the way she was told her cancer diagnosis was "Listen, you have a cancer. We're going to take you to theatre tomorrow and chop off your breast since you clearly don't need it." And she was like "Who says because I'm 65, I don't need my breast?" Right? And so, I was like "Okay, here we have a ton of problems!"

It's really about the perceptions of the worth and utility of women and their contribution. And the perception that "Well, you know, since you're clearly past childbearing…" Nobody wakes up one day and says this is a good day to lose my breast. So for me, it was really about how do we ensure that our patients are seen, heard, and respected. Somebody needs to be able to provide that service for women. And that's really how I wandered into breast surgery.

CANCER CONTROL: This explains so much of what I've seen written about you and what you've said.

MIRIAM MUTEBI: Healthcare professionals need to be educated or informed as much as the patients.

CANCER CONTROL: I imagine the response you were getting from your audience – the eyes of a deer looking into the headlights – was just a blank stare. Like "I don't recognize this …This never happened to me?"

MIRIAM MUTEBI: Yes, exactly. Exactly.

CANCER CONTROL: And your assumption that it had is interesting. I wonder if it's a generational thing? That your generation found that older generations weren't doing all the things you know are good practice?

MIRIAM MUTEBI: I would say, in fairness, there's almost been a shift – and not just in Africa but everywhere – away from the almost paternalistic approach to the practice of medicine. You know, when we literally came down from the mountain and told you to swallow two tablets. Right?

CANCER CONTROL: Ah, "the good old days".

MIRIAM MUTEBI: We're a lot more collaborative now, and it's more patient centred. In oncology we've gone through the whole spectrum where now it's really about shared decision-making. It tends to be the same, I would say, in many other specialities. There's been a shift from "Doctor knows best" to "We're partners in your health and giving you the information that you need in order to make the best decision". There's generally more openness to being questioned, but it's still a learned skill.

CANCER CONTROL: In what sense?

MIRIAM MUTEBI: In the sense that sometimes where there is a lack of openness to being questioned you have to do a deeper dive into where that stems from.

CANCER CONTROL: Where does that stem from?

MIRIAM MUTEBI: Sometimes it stems from ignorance. Like "Don't ask me questions, because if you ask me questions, then you're going to shine a spotlight and show that I don't know." And I think maybe some of the older clinicians had a very big problem with saying "I don't know." Whereas you'd find nowadays people are a lot more open; probably going a little to the other extreme where on occasion, your doctor is "googling" your responses sometimes in front of you. Which is why my patients sometimes tell me "I don't trust that doctor! They were Googling in front of me." But generally doctors are a little more open and things are better. I don't have a problem telling my patients "I don't know the answer to that. I would have to look at it. I would have to read up around it, or even refer you to maybe somebody who knows, or who has this as their speciality."

CANCER CONTROL: You're suggesting the doctor-patient relationship has mostly changed?

MIRIAM MUTEBI: I would say traditionally doctors were highly revered as the single source of knowledge, whereas now, with technology and the Internet and everything, there has been a democratization of knowledge. Our role has become less as a censor, more as custodians of how to make the best proper decisions. But even with the newer generation it's… "I'm sorry I'm going off on a tangent, but bear with me…"

CANCER CONTROL: Go ahead.

MIRIAM MUTEBI: One of the things we have had to reflect on as clinicians, maybe the one thing that we may have lost along the way, is our humanity. One of the things that we're trying to think about as educators which we never had to address before is: "How do you teach empathy?" Because we used to regard our training in medicine as almost like an apprenticeship. You mirror your seniors, and you practise how they practise. I think somewhere along the way, medicine started to become a "9 to 5", and we've almost come to the end of the spectrum where we're treating medicine like just a job. And that, I think, is also a problem. Don't get me wrong. In surgery and other fields, regulating the work hours has definitely made a difference. We would often do 72-hour shifts.

CANCER CONTROL: Brutal.

MIRIAM MUTEBI: Yes, it was not great, but I would say now that there is sometimes, an overinterpretation of regulated hours. It doesn't mean for instance, because it is it's five o'clock, you should leave the operating theatre… You should leave the patient on the table because you need to clock out. I would say that there's generally a trend towards less patient ownership.

When we were in medical school, even as a medical student, when you admit the patient to the ward, they were yours until discharge. You had to follow up the patient. You had to get the labs, you had to do the other things. But what we find now, sometimes due to the regulated hours, you find is that continuity of care only happens with the attending physician or surgeon. You're the only one who pretty much has a sense of what's actually happening to the patient, because everybody else is checking in and checking out for their areas, whereas for us it doesn't matter as the buck ultimately stops with you. Yes, it might be a little uncomfortable having to stay a little longer, but at the end of the day the patient has given you the privilege, for want of a better word of operating on them or caring for them when they're most vulnerable. And that does come with a certain trade off.

CANCER CONTROL: The privilege of having the patient's trust in you?

MIRIAM MUTEBI: Exactly. I think that's where we've swung the pendulum to the other extreme. It's one of those things we're trying to think about collectively: how do we reinstall empathy in our training? This is not just a nine-to-five job. This is a person. This is somebody. Having said that, I have often worked with very diligent and conscientious residents. The question is how do we amplify this across the board?

CANCER CONTROL: We're now clearly heading towards talking about AORTIC and research and training in cancer. Is the message here "Look, medicine and the care of patients is special?" That there's nothing else like this. It's unique. And we might have set hours and we might have shifts and so on, but actually it's special and you should remember that as healthcare professionals, there's no one else in the world doing this job except you?

MIRIAM MUTEBI: Exactly. And just wrapping up the journey, as a practicing surgeon, when you're treating women across the continuum and realizing that not only are many of them getting diagnosed with advanced disease, they're often not completing their care. And so really trying to think strategically around what is going on and how do we solve that? So that is why I had to go back to school because I had to learn more about this. That's why I decided to get my training in epidemiology and health systems research and to look at what are the barriers to care? And how can we design interventions that address those barriers?

AORTIC's mission is to look at how we can transform cancer care or cancer control in Africa, through collaborations in research, education, and advocacy to provide equitable and timely care to patients. Then, its broader aspiration is looking at how do we get patients, irrespective, of where they are in Africa, accessible, affordable, timely cost-effective quality care. This is really the ask.

CANCER CONTROL: How can this transformation be achieved?

MIRIAM MUTEBI: I would say AORTIC's strategy has been through three main pillars that almost reflect the three barriers or "buckets" to care that patients face.

The first bucket is financing, which is a major barrier because quite a number of patients are paying out of pocket for access to cancer care. We recently did work with the *Lancet Commission on Women, Power and Cancer* looking at what is the percentage of household expenditure that women in low- and middle-income countries face versus women in high-income countries. The women in high-income countries spent about 30% of their annual household expenditure on cancer care. I wonder if you have any idea about the amount women in low- and middle-income countries might spend?

CANCER CONTROL: Several times more.

MIRIAM MUTEBI: Yes, it's about 160% of annual household expenditure. So, is it any wonder that people are not completing their care? Don't get me wrong, there have been some attempts to try and improve patients completing their care. I remember when I was an intern, we would have to give chemotherapy as prescribed by the internist, because again, there weren't enough oncologists at the time. You would get a patient getting the first cycle of chemotherapy and just disappearing. And then they would come back six months later, and they're super excited because they've raised enough money for the next cycle.

CANCER CONTROL: When it was too late?

MIRIAM MUTEBI: Totally. And so I would say the significant thing that made a difference, at least in Kenya, was the social insurance that provides cover for some of the costs of the treatment, whether it's surgery, chemotherapy, or radiotherapy. So we're actually getting more patients to the finish line. Another challenge, when we're looking at finances, is that there's only so much leverage one has in the absence of enabling policy.

The second bucket is addressing the health system itself. We know that, on average, anyone in sub-Saharan Africa is going to see from four to six healthcare providers before a definitive diagnosis of their cancer is made. That's why we're moving the language away from "late presentation" because that's almost like blaming the patient for the late diagnosis when we know that patients are ping-ponging through our health systems before help is secured.

I've had numerous episodes where patients go to healthcare providers and they're in their thirties or forties, and again, people are still having that poster mentality where unless the lady is in her sixties and seventies, she can't possibly have anything related to cancer. Because most of them are of childbearing age; I would say 30% to 40% of my patients are under 40. So, they're coming in with lumps and are being told "It's nothing!" Or maybe they're breastfeeding at the time or pregnant, and so it's "No, no. This is nothing to worry about." And they're the ones self-advocating and coming back and saying "This is still growing." Or "something's not right." And sometimes they actually have to push in, in order for them to get the care that they need. There's really a gap that needs to be addressed at the primary healthcare setting, because these are the gatekeepers to care.

And then, of course, when you do get into the system, even when you're getting to navigate the system, you find maybe that's missing the agency, and the lack of skills. You're still not necessarily getting the quality care that you need in order to get you to the full treatment. And those are really some of the areas that are major barriers for patients.

The third bucket, that perhaps we don't talk about as much, is the social-cultural barriers that exist.

CANCER CONTROL: Are we talking stigma here? Or class?

MIRIAM MUTEBI: Yes. Stigma, which, to be completely honest, we found has nothing to do with levels of education.

CANCER CONTROL: Really?

MIRIAM MUTEBI: We did a study looking at both private and public hospitals in Kenya and Tanzania, and what we realized was that it really didn't matter about the levels of education or socioeconomic status. We interviewed patients in private hospitals and I've had patients who have been told: "Don't come home. You're literally half the woman you used to be!" I think that my assumption/hypothesis going in was that this was to do with levels of education, but this was not so. The reality is that there are many partners who are not supportive, regardless of education or socioeconomic status. But then, any chronic illness/condition sort of unmasks the underlying tensions in a relationship, and it almost acts as a trigger for some of these.

CANCER CONTROL: Is there data on this?

MIRIAM MUTEBI: I believe there have been small studies in Nigeria for instance and other parts of Africa. One such study looked at women three years into their cancer diagnosis. Eighty percent of women who'd been in a relationship prior to their diagnosis were actually either divorced or separated. These are staggering figures, albeit from a small sample, but it kind of tells of a trend happening in many parts of Africa. There are also some cultural elements. Sometimes there's a lot of cancer fatalism, where there's the belief that you're going to die from cancer; that you go to the hospital to die, which paradoxically is self-fulfilling when people get a cancer diagnosis and are using alternative therapies, and then only go to hospital when they're in extremis. That is how the myth is perpetuated, because you go in and you don't come out and people say "Why would I come in if I genuinely believe that cancer is not treatable?"

CANCER CONTROL: In our 2023 edition there was an excellent article on the language of cancer communication in Africa written by Hannah Simba and Valerie McCormack at IARC and yourself. Can you tell us what part language plays as a cultural barrier to cancer control?

MIRIAM MUTEBI: This is part of the work that we're doing with AORTIC and in collaboration with IARC, looking at the language of cancer. Kenya, for instance, has about 65 different dialects and Ethiopia probably has around 85 or so, but there isn't necessarily a specific word in dialect for cancer. What happens is that the many dialects would interpret it in direct translation with negative connotations as "the wound that never heals" or "the thing that will kill you". So if you're thinking about cancer as the wound that never heals, or the thing that would kill you, why, for heaven's sake, would you come to the hospital to get care, right? It doesn't make sense. You believe that you are going to die anyway. So, there's still a lot of cancer fatalism that needs to be addressed.

We've been trying to do that through advocacy and this includes to healthcare providers. The language we use can have either positive, neutral, or negative connotations and we're trying actively to get to the neutral definitions without negative connotations. The language that we use, from the health system perspective, is incredibly powerful and one has to be mindful of what the local interpretation of the screening and treatment process might be like, for example.

CANCER CONTROL: But our language about cancer isn't neutral, is it? We have reserved the term "malignant" solely for its description, and that is because we recognize its wickedness; its propensity to return after we believe we have been cured. If you're looking for an enemy, it's an enemy of all of us. We're all cell-based.

MIRIAM MUTEBI: Exactly. What I mean by "neutral" is that you don't want to oversell it, in the sense that you're having positive connotations to it, but you do want to avoid the negative connotation and just get to a neutral space so you're able to have a balanced conversation.

There's a real push back, at least from the people with lived experience, against the enemy or battle connotations. Some individuals may not want to be called "warriors" and some people have a real concern with the word "survivor". But, to answer your point, recognizing that it's definitely not benign and it is an intense experience, it's important to be respectful of that. These are things that do need to be acknowledged, even as we communicate to patients. I always like to joke and say "I'm in the hope business", because for the longest time, at least in Africa, it was basically cancer equals death. But I'm also not giving false hope. It's really giving a practical, balanced view that there is treatment at any stage of cancer and that the treatments are available that can potentially cure or control the disease and improve the quality of life.

CANCER CONTROL: You spoke earlier about empathy. I think it's normal for people to find it difficult to deal with someone else's suffering. It may not be part of one's natural set of responses. You actually have to be taught how to do it and, even then, I'm not sure how successful one is. You see suffering and you have to respect it. But it's finding the words… Sometimes, you don't need words, just holding a hand.

MIRIAM MUTEBI: Exactly. Beyond having to teach formal empathy, some of it is just basic common sense.

CANCER CONTROL: But the teaching of healthcare is a brutal thing. The hours, the work; you're brutalized to a certain extent. You come in with the best of intentions, all bright-eyed and bushy-tailed, and after five years…

MIRIAM MUTEBI: Yes, you find 80 patients waiting in your queue and you're thinking, how do I provide this? I have a colleague who's an anaesthetist, and he's like "You know, you're seeing 80 patients in a day, but the patient is only seeing one doctor, right? And so, for that one patient, are you giving one hundred percent?"

I know it's a big call to ask from us, but patients unfortunately do not have the luxury of seeing all the colleagues who do what you do. For them "For them you are it." And so, for that brief interaction of 15, 10, or even five minutes all you can say to yourself is 'How do I manage to infuse this interaction with "I see you. I hear you. I know this is tough, but we can do it if we go through 1, 2, 3?" And that may not take more than two or three extra minutes.

Part of the strategies that we've been looking at are communications strategies for healthcare providers seeing patients. Nobody says you have to do it all. Maybe the patient spends five to 10 minutes with you and a longer time with the breast care nurse going over some of the things that have been discussed, just so that at the end of the day the patient will feel heard, respected, and supported.

And so people have looked at what are the different models of communication, even bringing the caregivers on board and trying to get them to understand. Because that brings me to the third aspect of the cultural variance of Africa. In Africa, there's a vibrant sense of community and I always say that I love that about Africa. It doesn't matter where you are on the continent, people will welcome you and will support and feed you. But sometimes it becomes a double-edged sword, when it affects patient agency.

I'll give you an example. I have a patient who because of the size of the lesion would probably either have breast conservation therapy or a mastectomy. Usually we would lean toward breast conservation. Let's say then, you would advise the patient of the same, but you still have to go through the options. And sometimes patients will go home because they want to have a think about it. And then, two weeks later, they sometimes come back with a clan, you know? And the family spokesperson is saying: "We have decided…" And I'm like "Wait, wait, hang on a minute. Who's we?" And then it's like "We have decided she's going to have a mastectomy." And, you know, you're looking at this, and you're thinking "I know what the patient wants, because we've had this conversation. Why should she lean towards having a mastectomy?" But the patient says "Well, it doesn't matter what I want. They're the ones who are paying for it, so they get to decide."

CANCER CONTROL: Harsh.

MIRIAM MUTEBI: Yes. So it's really not just about giving women a voice. We talk about agency and ask "What does the patient want?" It's also about the financial support to ensure that her decisions are actually supported if she can't pay for it. Traditionally, in many parts of Africa, women are often not the primary determinants of the health seeking behaviour so they need either financial support, or sometimes even permission, in order for them to access care. It's a bit of a disaster where you're saying "Hey, you know all about agency, but we can't back it up with a system that's going to support your decision." So those are really some of the aspects that we do need to think about tweaking, even as we think about fully supporting our patients' wishes.

CANCER CONTROL: This ties in with your work on the *Lancet Commission on Women, Power, and Cancer*, and also your position at AORTIC. One of the questions I have to ask you – and it's an official question – is: Madame President, what are your plans for AORTIC?

MIRIAM MUTEBI: I could be cheeky and say "Plans for our patients to prosper. Plans to give them hope and the future."

CANCER CONTROL: And lo, right in front of our eyes she changes into a polished politician!

MIRIAM MUTEBI: But then, seriously, I will tell you about how we're actually doing that. As I was explaining earlier, we have three main arms: education and training, research, and advocacy. Through the education and training part we've been training clinicians all the way across the continuum of care. Right now, in collaboration with partners we are training primary healthcare providers, teaching them the basics of the signs and symptoms of high burden cancers, which in our setting are breast, cervical, prostate, colorectal, oesophageal, gastrointestinal (GI), and childhood cancers. And, going beyond that, getting them to appreciate the intricacies of the referral pathways in their setting, and also patient navigation. So that we actually do get and retain patients into the system.

Part of the additional training and education we're also doing, through a webinar-based series, and other in person modalities, is getting the healthcare workforce to really improve on the quality of care that they're providing; having ongoing conversations about things like magnitude of benefits. Because again, we have a young emerging workforce and there's a lot of enthusiasm to emulate other settings. How do we get all these shiny new toys in? And so we're always taking a pragmatic approach, saying "What are the basics of care delivery that one needs?" We can't be pushing for, say, complex immunotherapies when we don't even have the basics of chemotherapy. It doesn't mean that we don't push for that, but we do need to look at how we get the basics in place first, then build on that. So that's part of the conversation that we've been having, how to push for both, but prioritize needs.

I've just came from the AORTIC Best of ASCO Africa meeting in Addis Ababa, which was the first in-person, conference that we've had in this series, around access to quality care and customising solutions for Africa, that we have had. To be completely honest, I was just blown away. Our theme was around innovations and access to technologies and we had a simple mandate. What we did for these young oncologists was we said "This is the latest evidence. What we want you to do is interrogate this evidence and ask 'What does this look like for my patients? What are the implications? And what am I going to do when I travel back from Addis to my hospital?"

It was such a brilliant event! People were sitting down and discussing things like "These are my challenges. These are the things and opportunities I see. Does this make sense for my patients? No. Why not?" And this was because of 1, 2, 3. It was basically just discussing real-world practice, the challenges that we're having, and, more importantly, what are the opportunities?

For instance there's a brilliant study around exercise, improving our long-term outcomes for colorectal cancer patients. And so, of course, this was a little more complex, using some apps and other strategies. And we're like "Okay, but what does this look like for your urban or rural patients? How do you contextualize this evidence for your practice and for your settings? And honestly, I was just sitting there, watching them deconstruct then adapt and rebuild science for our settings and I was having a proud "Mother Hen" moment, thinking "These are my babies, Africa is in good hands!"

In that sense, I think the future of Africa is safe if these are the people who are going to move this forward; a hundred percent. It was such an inspiring meeting. It was so good to see people engaging with work, and really trying to see "How do we break this down and make this relevant to our settings?"

CANCER CONTROL: Those are the best sort of meetings – you want to go on and on!

MIRIAM MUTEBI: Yes, and we were saying "Listen guys we have to cut the session short and move on to the next session!"

CANCER CONTROL: What was the take-home message?

MIRIAM MUTEBI: I think, for me, it's really around "How do we tap into that and amplify that on a continental scale?" I mean, we definitely are having the forums and things that we're providing but then how can we collectively amplify those efforts? That's really part of the educational scope beyond the traditional didactic. It's really about pragmatic ways of delivering quality care in our setting, and I think pushing back against the maxim that low resources equals suboptimal care. And that's something that I definitely do not accept, because we know that any setting has resources. We need to talk about resource optimization and misuse, under-use, and over-use, and what that looks like in our setting. Simple things like avoiding serial CT scans every three months for patients who are on survivorship or follow-up care and the financial toxicity that brings. Because there's no support for that and patients are breaking the bank trying to get money to do that.

CANCER CONTROL: Well, the ghost of Universal Health Coverage is haunting all of us. Since the beginning of this year, with everything else that's happened, it seems to have receded as a possibility. People aren't talking about UHC so much anymore, which brings me on to the next question. *Cancer Control* is conducting its annual survey… we haven't approached you because we are already having this interview…. but the question is the same: "How have recent external events affected your work in cancer control?" What would be your answer?

MIRIAM MUTEBI: I'm probably going to sit on the fence a little bit, in saying that this is pretty much an evolving or moving target. We will probably have a little more clarity on the downstream effect and true impact of all of this in the next couple of years, but I would say the immediate impact has definitely been a pausing of many global oncology activities. So, whether it's research or collaborations or whatever, that has been the immediate effect. There's still a lot of uncertainty. Nobody is really sure. Is this definite? Is this going to be long term? Are there some things that are continuing to work, or some things that are not working at all? And so I would say it's a little early to reflect on what the implications are.

But it is important to get ahead of any disruptions to systems and you know, as we always say, make lemonade, or look for the silver lining. Perhaps it's an opportunity, like the pandemic, for us all to take stock and look at how we could do things differently in the future? I think it's forced us to an inflection point where we do need to sit down and think about how we can maybe do things differently, or in a more sustainable manner that encompasses a global approach to care going forward. I think we did that with the pandemic, so perhaps we need to think about how we could have a global approach to trying to solve the granular issues of local oncology in different settings. We haven't really engaged with that question as robustly as we needed to. I think we've sort of done things a certain kind of way for a while, and, like the pandemic, this is forcing us to take a beat and think about "Well, how can we work together differently? And how can we build back better?"

Because whether we look at it from a health system perspective or a geopolitical perspective, the truth is that the world is changing so we need to think about how we can change better, or evolve better, to support this changing world. And so that for me, is a real opportunity that we can leverage on. I think the downstream effects will emerge in time but the idea is for us to be proactive, and to use this moment to really rethink our paradigms.

CANCER CONTROL: Yes, the commonality between what we've had happening this year and the SARS-CoV-2 pandemic is that both have shown our vulnerabilities.

MIRIAM MUTEBI: Absolutely. Maybe this is a nice segue into one of the other initiatives we're doing, which is around research. One of the things that I'm most excited about, my biggest push at the moment, is trying to develop our continental research infrastructure. We do know that as a whole, cancer research in Africa is only about 8% of all African biomedical research, right? And if you put that in a global context, it's probably much lower. The work we've done at AORTIC, in collaboration with King's College London, is looking at the representation of cancer research in Africa, where I would say almost 67% of all African cancer research is being generated by five countries, mostly in North Africa. And so that begs the question: what is happening to the remaining 49? It's clearly an opportunity to start to shift this.

And, anecdotally we've had all these stories about how medications don't work as expected. We are looking at guidelines, and supported by trials and data that have been based predominantly on Caucasian populations. And so there's a real opportunity for us to try and think about how can we develop, generate, and get sustainable data that we can use for policies in our setting. And that's a really big part of the push that I've been trying to work on over this period.

A large part of what we've been trying to do in AORTIC over the last two years is to establish the Cancer Foundation to look at how to generate funding and support for micro-grants that can help answer basic health systems questions. And why that's important is because, for the longest time, research has not been something that's necessarily been intuitive in our curricula, as you will find in many medical schools across the globe. Outside Africa, even as an undergraduate, you would maybe do a year of research or at least have some dedicated research time.

In many training centres in Africa what happens is you'll get your first encounter with research probably as a postgraduate, where you have to develop a dissertation. Your supervisor is somebody who's done something similar, so their exposure and expertise is probably not as optimal as it could be. So how do we expand that infrastructure? Because even as we compete globally, we've realized that the questions that we want answered are not necessarily in tandem with the funding streams that exist.

I'll give you an example. We tried to look at what the continental priorities are? What are the burdens of cancer and what is the research that's being generated? We were able to compare those and we found with high burden cancers, like cervical, prostate, oesophageal, and GI, hardly any research was being done around these, whereas breast cancer and blood cancers almost have a commensurate level of research. There's a clear gap and opportunity to change this.

If we look at cervical cancer, where we have a 90% mortality, clearly there's a need to figure out what can we try to do to resolve this and ask "What is the main difference between the 49 countries and these top five countries that are leading cancer research in Africa? Who's paying for this?" What you realize is that the ones that have the highest research output are the countries that are having country-led initiatives or at least having skin in the game in terms of funding their own research.

In terms of looking at the priorities, which is something we also did, we looked at research priorities across the globe. We looked at Africa, Latin America, and Europe, and if you look at those charts there's no difference. What does that tell us? It tells us that there is no difference between Europe, Latin America, or African priorities, which is clearly not true. It just means that the funding streams are dictating the focus of research rather than the actual needs on the ground dictating the research. But at the end of the day it's "who pays the piper". If you're bringing in the money I can't tell you that you can only do research on my priorities. You're going to do it according to your priorities.

And so we need to think about how we get to a model where we're generating grassroots research that speaks to the needs on the ground? And how do we then find a way of tweaking the current funding streams to reflect that? How do we shift efforts so that we can get alignment between local researchers and local and international funders?

This is now part of our work because our young oncologists have said that the work they want to do is not necessarily of interest to anyone else. For instance, they want to answer simple, basic questions – and you would think that this is fairly basic, but we don't even have the data on what's happening to their patients. What are the outcomes? So, somebody writes a nice small grant "I'm working at my setting, and I would like to know what's happening to my patients, and what are their outcomes ?" and they are in the global competition pool where they're going neck to neck with somebody who's working with an innovative new molecule. I mean, this research may not reflect a global hot priority, but may be essential to cancer control and planning in that ecosystem. Don't get me wrong, it is important to have both questions answered, but we're fundamentally saying how do we then create the platform or the ecosystem that actually generates this local data? And that's through the micro-grants that we have launched.

We had the first call in September. It's all about trying to answer basic health system questions in a cohesive manner that actually builds up the collective of that data and providing a way that we can then collate that data to make real fundamental change.

CANCER CONTROL: This sounds eminently sensible. Who's funding the micro-grants?

MIRIAM MUTEBI: So, I'm hoping to get this plug in because we're going to use this platform to get more funding. We have two partners so far: BioUsawa, which is an African-based company that are trying to produce their own monoclonal antibodies on the Continent; and collaborations through the Henry Ford Center, through their Precision Medicine for Advanced Breast Cancer collaboration. But we're definitely trying to get more funding for the next run. You would think that this makes sense but people are always sceptical, so that sometimes you have to show proof of concept. That's what we're trying to do with this initial run, and trying to see whether we're able to encourage more partnerships and support for this. This is the direction AORTIC is going be heading and in support of that in another couple of months we will hopefully be launching the AORTIC journal.

CANCER CONTROL: Sorry? The AORTIC journal?

MIRIAM MUTEBI: Yes, fresh off the press – you heard it here first! Part of the thinking behind the micro-grants is also the capacity building. So it's not just giving you some seed funding to answer basic questions. It's providing you with support for "How do I write a grant? How do I share my findings? How do I translate that into manuscripts? How do I disseminate that to a regional audience?"

CANCER CONTROL: And now you've got a journal to publish the results.

MIRIAM MUTEBI: Now we've got a journal to help facilitate these learnings, exactly.

CANCER CONTROL: Excuse me while I stand on my soapbox for a moment, but you were talking about the bibliometric exercise that Ajay and Richard and the guys at King's were helping you with. I looked at this, oh gosh! many, many years ago, and it was abundantly clear even then that Africa, as a continent, was still massively underrepresented in the published journals. It really is a case of you've got to grow your own, because otherwise you're always dependent on some guy in Phoenix, Arizona, or Tavistock Square or wherever.

MIRIAM MUTEBI: Absolutely... but then it is equally important to invite the same guys from Phoenix, etc., to collaborate and develop opportunities for bidirectional learning.

CANCER CONTROL: You began by saying "These breast cancer patients didn't look at all like what I was expecting. They were meant to be like 60-year-old nuns, and she's under 40 and she's got a child at the breast… ." And that's because the published research had shown that two-thirds of breast cancer patients were over 65. Sure, in our country. But not in yours.

MIRIAM MUTEBI: Exactly! The context matters and this is why I'm really pushing for the journal, because… I'll give you an example.

A few years ago, we did a study on breast cancer patients and tried to look at the 5-year survival. We honestly searched across the continent, and we couldn't find anybody who had that kind of data. And so we submitted to an eminent journal – which shall remain nameless – and their response was, "Oh, gosh, I think you should try and do some kind of multicentre study. As a global community, we're moving towards multicentre collaborative work…."

And we were like "You don't get it. You just don't get it." Because anybody in Africa is like "Wow! How did you manage to get this data?" Because nobody, for a myriad of reasons at the time, had any significant data for patients beyond one or two years. This is because a large number of patients dropped out of care, tracking mechanisms were not robust and so on. This was from a well-meaning, but not optimally informed, external editor.

And I'm thinking, I'm sorry, but you don't get it and rather than arguing with you we should change the game and see how we can provide platforms where people are generating prevalence data that we can learn from, and have opportunities to collaborate on. So, the journal is part of the opportunity for expanding a platform that provides an area where people can disseminate data, use that, and really build that sort of research ecosystem.

CANCER CONTROL: This is a good point to segue into the third arm of what AORTIC does: the advocacy.

MIRIAM MUTEBI: I think it's a universally acknowledged truth that at the end of the day, any sustainable cancer control efforts still come down to finance: "who's paying the piper?" And so there's clearly a need to have a more nuanced approach to advocacy. I think, initially, in African oncology at least, our perception of advocacy was basically to hold up a placard and demand our rights. What isn't commonly known about AORTIC is that it has a long history of developing advocacy. In fact, when I first joined AORTIC in 2013, it was as a cancer advocate. They were giving a masterclass in cancer advocacy training and I signed up for that.

It's really worth thinking about what are the different aspects of advocacy that need to happen? One is political advocacy in the sense that we do need to talk to our policy leaders in a language they understand.

As clinicians we tend to give facts and figures and then notice that their eyes are glazing over. Or sometimes, from a civil society or lived experience perspective, you find the contribution around advocacy would be sharing stories. This is an incredibly powerful tool, but needs to be harnessed and this hasn't been defined.... better in order to move the needle. And so, training CSOs and people with lived experience around political advocacy is some of the ongoing work that AORTIC is doing in collaboration with partners. Questions such as "How do you consolidate your 'ask' to policymakers? How do you use your stories to support the 'ask'? How do you move the needle forward?" And that's really one of the strong aspects that AORTIC is championing.

We've also done research advocacy training where we have trained CSOs and people with lived experience to sit on IRBs; how to ask the right questions, how to ensure that the research community still has that tie-in to the communities they are studying. How to ensure the research is truly participatory. So, there's really a lot of advocacy efforts that are ongoing. We've recently revived our Advocacy Special Interest Group and those are some of the areas that we are looking at.

Of course, there are other aspects of advocacy that we want to expand, along with partners, because there's still quite a bit of legal advocacy that's needed in our setting. We have patients getting fired from their jobs because of their cancer diagnosis, with employers saying "Oh, you're taking too many days off" or that they just can't be bothered.

CANCER CONTROL: That's really the financial cultural change that's necessary.

MIRIAM MUTEBI: Exactly. Because people still need to have their chemo or other treatments and they will have to pay for it, and you shouldn't be in a position of having to have either chemo or pay your rent or pay for your meals. And we do need to develop things like the "right to be forgotten". That's not a conversation we've even started to engage with yet. But as we're seeing more and more patients getting through treatment successfully and living for years on end, these are real issues that we have to start to manage proactively.

CANCER CONTROL: Do you think the policymakers are aware of the likelihood of there being quite a steep increase in cancer incidence over the next 30 years? That's what IARC data are showing. And the financial consequences of that? Because, as you know, the cost implications of a cancer diagnosis ripple out across and beyond families into the economy. Do they recognize that this is coming down track, or are they like our politicians, thinking mainly in the short term?

MIRIAM MUTEBI: I would say there is a general awareness, especially, for instance, in Kenya where there's been a definite effort towards building systems, decentralizing care, and expanding the workforce, but there's a lot of heterogeneity that exists from country to country. I think that there has been a definite increase in the awareness of policymakers lately around cancer as an emerging problem. And how do we know this? We've seen this in the number of national cancer control plans that have been developed within the last 10 years, which have increased by almost 50%.

Where we would probably need to work with policymakers is, for the want of a better word, "eradicating" the sense of cancer fatalism, because quite a number of them still believe "Well, you're going to die, why are we spending money?"

And the second challenge is that cancer, compared to other medical conditions, is also expensive to treat. So, when they say "Yes, we acknowledge it's a problem, but we don't have the money for cancer care", I think we need to push back against the all or nothing mentality. Because sometimes the mentality is "Well, if I can't have the most state-of-the-art scanning equipment, then I can't come up with any sort of cancer control programme."

So it's really about shifting the narrative around to health as an investment rather than an expenditure. and emphasizing the early prevention strategies; showing policymakers the benefits of savings earned. If we take, for instance, something like breast cancer or even women's cancers in general, the causes of every two out of three women's premature deaths, that's women under 50 years who are the majority of the blue-collar workers in many countries; who are basically supporting the economy. How does it make sense not to invest in getting screening and detecting this early, starting treatment early? And we don't even have to talk about maternal orphans caused by female cancers and that sort of downstream effect on the family and economy. It's about getting them to rethink approaches. How do we deconstruct this daunting term cancer control? How do we break it down into doable portions and phased approaches that make sense for the setting?

I know WHO worked with the Kenyan government to look at an investment case for early detection strategies. They were looking at mammogram as opposed to CBE and they showed a minimal difference in doing a CBE versus doing mammography in terms of stage shifting when deployed as an early detection strategy. But if you look at the difference in capital required for mammography screening versus coordinated CBE exam, it's chalk and cheese. So, it's about looking at how do we build systems that we want within the resources that we have, what is the value added that we can develop and amplify?

And again, with policymakers we're also trying to emphasize looking at regional approaches rather than single country approaches because, for now, every country cannot have PET scans or state-of-the-art technology across the board. But if we look at how we increase fluidity of resources related to the workforce across these different borders, irrespective of where they are, or facilities that ease the movement of healthcare professionals across regions, then we're able to build truly regional centres of excellence in key areas that can support a lot of different dimensions, and that sometimes actually helps.

Then even things like basic access or procurement of medications. You might not know this, but currently African patients pay three to four times the cost of a drug in a similar low- and middle-income country. And if you take a deeper dive into the reasons why, the manufacturers are saying "Well, it's a small market…" and so on. So, we're saying how about we develop regional agreements and procurement, so that we're able to negotiate and start telling policymakers and industry "Listen, projections suggest we're going to be your biggest market in the next 10 years. It makes sense that we start to engage in a sustainable manner. We're not asking for a handout, No, no, no! Let's make a sustainable investment case so that you're benefiting. You still need to run your company and ensure supply. How do we provide treatment at a cost that's not going to break the bank and that keeps you sustainable enough for you to run your business and continue to generate these medications that are going to be increasingly needed, and ensure a constant and consistent supply where needed?"

CANCER CONTROL: Yes, because if nothing else changes the future will be harder than it is now and that is a poor inheritance to leave to the next generation.

MIRIAM MUTEBI: This is a real issue. Africa is a young continent. People getting cancer are technically youths; roughly 40% of our patients are under 40. So what are we doing about that? Looking at the projection of this growing cancer burden, it is imperative that we think about how we're going to leverage innovations and technology to mitigate some of the gaps in terms of the workforce. Because if we only go through the traditional route of training in colleges and workforce expansion, that takes you anywhere from 10 years or so from start to finish. But between and beyond that, how are we using technology or innovation to plug into the health system gaps?

CANCER CONTROL: Thank you so much for sparing the time to talk with us. You have been extraordinarily generous. I only have a couple more questions, if you have the time. The first is: having said all you have said about what can be done in Africa, do you feel positive about the future?

MIRIAM MUTEBI: A hundred percent. A hundred percent, after my "Mother Hen" moment! I really feel that there's so much going for the continent. We have the fastest growing economies. We have a vibrant and expanding workforce. Everybody's enthusiastic about making a change and making a difference. It's just thinking through how to cohesively consolidate efforts that help us to gain traction. But I would say there's been a general awakening enthusiasm to impact care and so it's really about, just thinking strategically how to tap into that, expand that and amplify that in a broader regional setting that I believe is really, truly going to make a difference.

And it's not just the health workforce. Even from the grassroots level there's been so much more engagement from civil society organizations, normalizing conversations around cancers and their management. We've seen growth and momentum in different countries. I reference Kenya, because that's my closest reference, where the CSOs have expanded and actually come under a single umbrella body KENCO. KENCO coordinates all the cancer-related advocacy activities for the country. What we realized was that everybody was focusing on screening. So we were saying "Let's take a step back. How do we have some people advocating for survivorship? How do we have some people advocating for diagnostics or treatment? Because it shouldn't be just screening, screening, screening; it's the entire patient journey.

Also, there's been such a big movement that states currently any technical working group of the Ministry has to have at least people with lived experience or cancer advocates serving on the technical groups for the Ministry, and that's huge as their contributions are invaluable

CANCER CONTROL: That's a huge advancement.

MIRIAM MUTEBI: Exactly, in terms of getting people out there. There's more global recognition of the value of having people with lived experience sitting in and sharing their insights. And so I would say, that's why I'm super optimistic. Yes, the burden is rising. Yes, challenges exist, but there are clear opportunities and the drive and enthusiasm to make a difference. As I said earlier "I am in the hope business." Yes, I'm truly optimistic.

CANCER CONTROL: The next question is, can you talk about this yen for flying. Are you going for a pilot's licence?

MIRIAM MUTEBI: Yes, yes. I'm getting in my hours, but the challenge is that, in order to get your private pilot's licence, you need to sit the ground exam and that takes time. I've talked to my trainers, and you need at least three to six months' dedicated reading, because it's a whole lot of the things that you've kind of run away from since high school: physics, geography, map reading, and so on. And then, of course, a lot of the exam relies on you knowing international air law and local law, so I'm thinking I need a little more dedicated time to close on this. I haven't quite gotten it yet, but I'm hoping to.

In the meantime, I'm still trying to get my hours in. It's one of those things I had as a child, a life-long bucket list, and somehow what was always at the top of that was becoming a flying doctor. And I blame my folks because where I grew up in Nairobi was a place called Langata.

CANCER CONTROL: Near the airport?

MIRIAM MUTEBI: Yes, very near what they call the Wilson Airport, where they used to have Amref, which is the African Medical Relief services. There used to be flying doctors that would go around different parts of the country.

CANCER CONTROL: That's so cool!

MIRIAM MUTEBI: Exactly. The reason that I actually joined medicine initially was because I wanted to be a flying doctor. And so, I look at my bucket list at 10, I look at my bucket list at 20 and at 25, and it's still to become a flying doctor. So I said to myself "Come on, Miriam, let's actually do it."

CANCER CONTROL: I thought that it was just to be a pilot, but actually you can't shake it off, you need to be a flying doctor!

MIRIAM MUTEBI: And because we also do quite a bit of breast outreach in different settings. If there's a quicker way of getting there, rather than a 10 to 15 hour journey by road, if I can get there in an hour or less, then, you know…

CANCER CONTROL: One more question, then we really will finish. What advice would you give Miriam aged 17 years, if you could?

MIRIAM MUTEBI: Oh, wow! I think the first thing I would probably say is "Believe in your vision and believe in yourself. Because sometimes what happens is that not everyone can see your vision or your direction. And that's okay."

I think growing up iteratively, you have things that you want to do, but then you talk to people who discourage you. Sometimes it doesn't mean that they're not well-meaning. It's just that they don't necessarily have the context, or see what you're getting at. So I would say "Have faith and belief in your vision and what you want to accomplish." There's going to be a lot of people waiting to talk you out of it, and for every person saying something can be done, there are at least 10 people telling you exactly how and why it can't. So I would just say, you know, "Believe in yourself and keep going!"

The other thing I would say is, fortunately, or unfortunately there is no substitute for hard work. There's always going to be an opportunity cost to what you want out of life, but there are benefits. You know, sometimes I think we're living in the age of instant gratification. Yes, we may have gotten a little more efficient at doing certain things, but in order for you to be really good or really engaged with something, you do need to put in the time and effort.

CANCER CONTROL: And it does reward you.

MIRIAM MUTEBI: Yes, exactly. And you can't cut corners, or figure "I'm just going to take shortcuts." You do need to put in the time, and that's the reality. Nothing in life is ever… well, at least my experience…nothing in life is handed to you on a golden platter. You have to actively go and do the time. Do the work in order to get to where you want to be.

But also, what I would say is enjoy the process and the journey, because sometimes we have tunnel vision. We're so focused on where we want to get that we forget that Life actually happens in the gentler parts of the process and the journey. That's where you do, or get, most of your learning and experience. And when you look back, it's not about where you've got to, but how you got there that really makes a difference.

CANCER CONTROL: It's also on the journey that you make your friends.

MIRIAM MUTEBI: Exactly, and where you interact, iterate. And where you learn to fail and rise. As Samuel Beckett says, you know, "Fail again. Fail better."

CANCER CONTROL: I've heard it said about luck, that it's surprising how much more luck you get from working hard. The harder you work, the more luck you get.

MIRIAM MUTEBI: I can't remember who it was that said "Chance favours the prepared mind."

CANCER CONTROL: It was Louis Pasteur.

MIRIAM MUTEBI: It's quite right. It's the intersect of hard work and opportunity. That's what we're really labelling as "luck".

CANCER CONTROL: Well, we've been very lucky indeed, having this opportunity to speak with you, Miriam. Thank you for giving up so much of your time.

MIRIAM MUTEBI: No worries. It was nice catching up and having the opportunity to, how do I say, pontificate about the subjects I like best! Thanks for the chance. ■